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ABSTRACT

This paper discusses perspectives on the relationship between parents and professionals in the diagnosis and treatment of children with autism. In the first section, the mother of an autistic adult recounts her early experiences in trying to obtain needed services and support for her then young child. A professional then describes the negative and inappropriate professional attitudes and approaches illustrated in the mother's narrative. It is noted that parents have important and reliable information to share about their child, and ignoring this information can result in delay in necessary services and enormous additional stress on the family. The following inappropriate professional responses are illustrated: blame and scapegoating of parents, failure to share information openly, lack of parent-professional partnership, permissive approach to treatment, and transient nature of professional involvement. The TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children) program in North Carolina is then presented as a model for meeting the needs of children with autism and their families in a collaborative manner, based on mutuality of trust and respect. The TEACCH program involves parents in the diagnosis and treatment process, integrates the program into the community, and provides continuity of service over time. (JDD)

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Parents and Professionals: Working Together

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In this paper, we will discuss perspectives on the relationship between parents and professional in the diagnosis and treatment of children with autism and other severe developmental disorders. In the first section, the mother of an autistic adult will recount her early experiences in trying to obtain needed services and support for her young child. These personal events are vividly described and serve as clinical data for the discussion which follows. The professional perspective covers the negative and inappropriate attitudes and approaches illustrated in the mother's narrative. The TEACCH program in North Carolina is then presented as a model for systematically meeting the needs of children with autism and their families in a collaborative manner, based on mutuality of trust and respect.

JOSHUA'S STORY

For every mother of a handicapped child, there is the moment when she leaves the ranks of parents with normal children, and steps upon a kind of treadmill, from which she is never to be released.

For me, this moment came at a Well Baby Clinic in Willow Run, Michigan. Sponsored by the State Department of Health, the clinic was run for the benefit of low-income families living at the Willow Run Housing Project. We were a student family, living with our 2-year-old son, Joshua, while my husband, Dan, worked for his Master's degree at the University of Michigan under the "G.I. Bill."

I had taken Joshua to the clinic for his periodic examination. While I was waiting with the other mothers, Joshua never stopped running around the room. When my turn came, the nurse said to me: "You know--you've got a hyperactive kid there."

This was not to be the last time I made the mistake of thinking I understood English. I thought I understood what "hyperactive" meant. I could certainly agree with her: Joshua was indeed hyperactive. What I didn't realize was that by "hyperactive" she meant something with a medical connotation.

We parents are often disabled by the technical language professionals use. This not only applies to spoken language, but to the language of journals and books. We often attempt to read these in a vain effort to understand what the professionals have said. Professionals should never assume their clients understand these technical terms; they should either explain the terms on the spot, or arrange a time when this can be done.

In my case, the nurse, using an ambiguous term, had given me a signal--a signal which did not register.

Our son's appearance as well as his behavior began to change. He had been a happy, handsome, smiling baby. Now his eyes were dark-circled, and his face had a strained, hectic look. He seemed to be crying and running all the time.

A friend of ours who was a medical student suggested that we take him to a mental hygiene clinic near Willow Run in Ypsilanti.

That was the beginning of a period which lasted for many years--a period which I wish I could forget. The professionals' approach was always the same: if your child has a problem, the problem doesn't exist with the child, but with his parents, particularly his mother.

The young workers at the Ypsilanti clinic didn't seem the least bit interested in Joshua, although we had brought him with us, thinking his behavior would speak for itself. Instead, they insisted that they wanted to work with us; we were the ones needing help.

Maybe, in the light of late '40's doctrine, they were correct; but some attempt to treat Joshua would have given us a little comfort; we would have felt that something was being done for him.

After a couple of sessions, totally frustrated, we stopped attending the clinic.

At last my husband received his degree. We moved to the pleasant city of Portland, Maine, where he had a good job. We also had another baby, a son, Max.

But things did not get any better for Joshua. When we enrolled him in a nursery school, it was not long before we were asked to remove him.

We went to our pediatrician, a brisk, no-nonsense type, who exuded an air of competence and authority, and was reputed to be one of the city's best. A tentative suggestion that something was wrong with Joshua was met with a haughty lift of the eyebrow, tacitly implying: "Just when did you get your medical degree?"

"Joshua is normal," he reassured us, "perhaps a bit slow in his development."

The amount of power vouchsafed to pediatricians by young parents with their first child is enormous. Only subsequent experience with other children can provide parents with the self-confidence to differ with their pediatrician's professional opinion. Yet a secure, knowledgeable pediatrician should be able to treat parents as his equals. In all those years of turmoil, never once did our pediatrician concern himself with anything other than Joshua's physical well-being.

So we waited six months, hoping Joshua would "mature" enough to be enrolled in a summer day camp. Once more there was the all-too-familiar phone call: the camp director said that Joshua had attacked several children and was too hyperactive to handle.

We could delude ourselves no longer. Something was terribly wrong. Despite what our pediatrician had said, we had to get help. But where?

At that time, there was only one psychiatrist in the city of Portland. Dr. Phelps was a brusque man, whose examination took about half-an-hour.

Among other things, he had Joshua, who had been racing up and down stairs before he was a year old, demonstrate how he could walk up and down a flight of stairs! Dr. Phelps undoubtedly had a valid reason for this; for us parents, it was mystifying.

Just as technical language may mystify, so may diagnostic techniques. Couldn't it be possible for the professional to explain what he was trying to find out--and why? Isn't it possible that the client might be able to point out symptoms and/or characteristics which the professional might have overlooked?

Dr. Phelps laconically announced his verdict: Joshua was retarded.

For our part, we rejected the diagnosis out-of-hand.

Parental rejection of a diagnosis of "retarded" is not unusual. In our case, however, our feeling was: "Here's a child who has walked since he was ten-and-one-half-months old; whose expression was bright, alert, absolutely aware; who began to develop normally--but who now seems upset." Although we knew virtually nothing about mental retardation, the psychiatrist's diagnosis didn't seem to fit Joshua's condition.

Dr. Phelps did have something else to say, however.

It was obvious to him, he said, that I was having some kind of emotional problem in relation to Joshua. I should therefore come to him for treatment.

Without any argument, I meekly agreed.

Since this presented us with a financial problem, Dr. Phelps gave me the opportunity to enter a therapy group he had created. Once again I agreed.

The therapy group proved to be very upsetting.

At home I had a child who was raising hell almost 16 hours a day; a child who was obviously very sick--but who was getting no professional attention at all. The only therapy available to our family was--mine.

On the other hand, the group was not based upon similarity of interest. Its members were not even parents of children with problems, much less children who were retarded or emotionally disturbed. Instead, it was made-up of troubled adolescents, couples on the verge of divorce, a would-be suicide, an alcoholic, and so on.

At some other time I think I might have been fascinated by these people, and might have derived something from my contact with them; but I was so anxious about our son, I found the experience utterly frustrating.

Perhaps this is the time to go into the subject of parental therapy groups. I am not against them. On the contrary, I think they may be very rewarding. The question is: if, in a small community, it may be difficult or well-nigh impossible to find enough candidates for a suitable group, is it worthwhile to place a parent with a serious problem in a heterogeneous group simply as a means of fitting in one more body?

A physician-friend suggested that we take Joshua to Children's Hospital, Boston, one of the great children's hospitals of the world. He offered to arrange for a complete "work-up" in the Department of Neurology.

We left Joshua at the hospital; and at last, after a miserable week of waiting, presented ourselves to Dr. Brothers, the neurologist in charge of Joshua's case.

Cordially, he invited us to sit-in with the experts while they gave their reports on their week's observation. Joshua had been given a complete examination: electroencephalogram, blood tests, psychological tests, "the works."

We had been sitting with the "team" for only a brief time, listening to the psychologist make her report, when we were asked to leave. It appeared that we were not to be privy to the discussion. The dichotomy--the gap between professionals and parents--which we were to experience over and over again--had surfaced. Dr. Brothers, with some embarrassment, asked us to meet with him after the conference was over.

When we did sit down together, the results seemed reassuring.

Joshua was normal, we were told. The electroencephalogram hadn't revealed any brain damage. What he was suffering from was only a temporary disturbance; he could recover, with proper treatment.

"What is this to be?" we asked.

"Total permissiveness," he replied.

Everything was to be allowed, within the bounds of Joshua's physical safety. Family pressures had undoubtedly caused his emotional problem; they must be removed. This was the key to his recovery.

We know, now, that this advice was exactly wrong.

Still, the doctor's prognosis was hopeful. We were full of joy.

After Joshua signed a release, 27 years later, I received the Children's Hospital report. We had never seen it; we had received only Dr. Brothers' oral summary. The written report had gone to our physician-friend.

Reading it, I could well understand why our friend never showed it to us.

"The accused"--us--had supplied all of the material necessary to convict. How nicely we had cooperated! Among the sentences were nuggets like:

"his tendency to resist and to become aggressive and unhappy were a result of the pressure placed upon him by his family"

"pressure on child and demands that were beyond his ability"

"Mother's second pregnancy and her consequent inability to devote any time to the child."

Dr. Brothers, we remember, had seemed so sympathetic!

Undoubtedly we were told all the things said in the report; but we remember it quite differently.

Based upon the Children's Hospital record, the diagnosis was certainly consistent; we had cooperated very well in providing them the Procrustean bed.

Even though the verdict, as in our case, was embarrassing to us, we not only had the right to see it, but to confront those who promulgated it. The whole situation resembled a trial: with the professionals as judge and jury, and us, the clients, as the accused in the dock.

Everyone should have been satisfied by the Children's Hospital report. Only one thing was wrong: it left us nowhere.

Since Joshua was so hyperactive and upset, it was impossible to get a babysitter for him. I decided to hire a sitter for the baby, and go out with Joshua myself. Since what he wanted to do was run, I let him run, running with him.

I eventually came to realize that I couldn't run with Joshua indefinitely. There had to be someone, somewhere, who could help us. We couldn't continue to be "closet parents," pretending to ourselves and to the world that we had a child whose problems were only "temporary."

It was then I remembered that when the day camp head had called to request that we remove Joshua from her camp, she had added that she had telephoned an agency, the Children's Service Bureau, and told a social worker there about Joshua. She had suggested that I get in touch with the agency.

Thus far, my comments on professionals have been critical. From this point on, however, I have many positive things to say.

In this case, I would like to point out that the day camp director, upon requesting us to remove our son from her camp, had not merely rid herself of a problem; she had also attempted to be part of its solution.

I telephoned the agency for an appointment; and not too long thereafter we went with Joshua to see the social worker.

Our misgivings upon approaching the agency were considerable. Three times before, in Ypsilanti, Portland, and Boston, we had appealed to professionals for help with Joshua, and been met with the same response: either a refusal to see him, and/or an indictment of us, his parents.

Difficult as this was to accept, we were once again applying for assistance, aware that we would probably receive another dose of the same; but there didn't seem anything else to do.

The atmosphere of the Bureau was pleasantly neutral. The receptionist was friendly, and put us at our ease. We were not kept waiting long. Just off the waiting room, in a cubbyhole of an office, we met Louise Citrine, the social worker.

For the next year she was to see all three of us: my husband and me, singly and together, and Joshua, for play therapy.

Louise's play therapy with Joshua was not conducted on an intensive level; but it did, at least, help to alleviate some of our overwhelming anxiety about him. At least someone was at last seeing him!

Louise's approach towards us was: "Look: we're all educated, intelligent, well-intentioned human beings." She didn't talk down to us, or behave as if we had committed a great crime.

From week-to-week we discussed the situation in a friendly, relaxed way. The overwhelming sense of guilt which the other professionals had seemed to foster no

longer blocked us from looking at our problem. Together we explored the next step to take.

"The experts at Children's Hospital believe that Joshua is normal," I told Louise. "They feel it is a temporary problem. I'm sure that by the time he reaches age 5, all this developmental and emotional business will disappear. He'll be able to go to kindergarten with the rest of the 5-year-olds."

Louise didn't argue with me. Instead, she proposed sending Joshua to a private kindergarten. In a smaller class, he might be able to get the special attention he needed.

After I met briefly with the headmaster of the well-known private school Louise recommended, and explained the situation to him, he agreed to enroll Joshua.

It was with much trepidation that I left Joshua to his new kindergarten teacher that first day of school. She was able to remember her experience with him in vivid detail 19 years later.

"I'll never forget the first day I met Joshua!" she exclaimed. "It was my very first day. In full view of the assembled mothers, Joshua went over to the shelves and swooped everything off.

"One of the mothers was dumbstruck. When she recovered, she asked me, point-blank: 'What are you going to do about that?'"

"I mumbled something, heading in Joshua's direction, and began putting things back. I went through the motions of having him help me; I really put things back, because he was very limp when it came to doing directed things.

"At the end of the day, I went down to see the headmaster, very angry. 'Either he goes or I go,' I said."

The headmaster was most sympathetic, and suggested that she go down to the Children's Service Bureau and talk with Louise.

When she discovered that Louise had been consulting with us, she felt reassured. Her initial apprehension quieted, she settled down to deal with Joshua for the remainder of the year.

So Joshua was nicely tucked away in the kindergarten in the mornings. Nobody complained to us about him. From September to June, everything seemed fine. And then we received the final quarterly report in June. The bottom line destroyed our brief illusion of normality: "We recommend that Joshua not return in the Fall," it said.

We asked for a conference. The kindergarten teacher met with us. I still wince in retrospect, when I think of that meeting. How could we have been so obtuse?

We had received excellent, detailed quarterly reports; but nothing had registered. Some sort of unconscious device had just not allowed the reports to penetrate our defenses.

So after a year's grace, we were forced to face a very grave situation: normal or otherwise, our child couldn't return to school.

Slowly, patiently, Louise led us to accept the painful idea of sending Joshua away to a treatment home. But in 1951 there was no treatment facility for emotionally disturbed children in Maine. The place closest to us geographically was the Bradley Home in Providence, Rhode Island. But the Bradley Home rejected our application, on the grounds that, judging from Louise's report, Joshua was mentally retarded.

We were in a state of total despair.

With her year's work in a shambles, Louise persisted in trying to find another solution to our problem. She learned that there was a new demonstration mental health clinic just across the street from the Children's Service Bureau. It was reputed to have a very well-regarded clinical psychologist. Upon the promise

that I would see an approved psychiatrist in Boston, she was able to get Joshua accepted by the clinic.

In Louise Citrine we found a superb social worker. Among the techniques which she practiced with us was her willingness to go along with us, not to argue; to help us discover the truth for ourselves. She also realized that it was necessary to be seen to be helping Joshua, in order to allay our anxiety enough to get us to work on our problem. But most important of all, she had the patients and persistence to stick with us, not only when she must have felt we were wrong, but to deal with the bureaucratic problems that would have defeated us.

Doris Perry, the clinic's psychologist, was probably the single most important factor in Joshua's rescue.

Then over 60, she had had extensive training and experience, including graduate work at Columbia, and collaboration with Dr. Gesell at Yale.

What she and our son did in the small, plain room at the clinic was their private affair; but we did sit in on conferences with her, the psychiatrist, and the social worker. At these conferences she would report on what she and Joshua had been doing, and make suggestions as to how we, his parents, might be able to help him or better manage our mutual existence.

The most valuable thing she provided was an imaginative, innovative approach. We learned from her to use whatever our son was doing at the moment as the key to carrying forward that particular activity one step further. We learned to look at his play as an important clue towards understanding and helping him in his development.

I could give you many examples of this, some of them quite dramatic. One will have to do.

By the age of 13, despite all that devoted teaching could do, he still could not read or write. At one conference, Miss Perry suggested that we should try to

take advantage of his love of music. The accordion, she suggested, was an instrument which he might be taught to play by rote, since by pressing a single button one can obtain a whole chord.

We discovered that there was a commercial music school which offered accordion lessons if you bought an accordion. What we hadn't counted on was that the lessons were to be given by a first-rate teacher. She decided to form an accordion band, and to teach the students how to read music.

When Joshua came home, and showed us that he could read music, I became very excited.

"If he can be taught to recognize notes on a staff, he can recognize letters on a page," I said.

I called his school, and begged his teacher to try to teach him to read just one more time.

Within a year he was reading and writing; within two years, he was writing in cursive script. With these new tools, he was able to acquire the equivalent of a ninth grade education.

But a neurological problem did not allow his penmanship to develop beyond that of a 6-year-old's.

That didn't faze Miss Perry.

"Teach him to typewrite," she suggested.

We got a teenage student in a commercial high school class to do just that.

Miss Perry chose to take her yearly vacation towards the end of September, when she would rent a cabin by the sea. The season being over, she had the place to herself.

Since, in a child's scale of time, two weeks can seem forever, she always made sure that each of her "children" had a day with her at the beach, accompanied by his or her parents; she would not let them feel abandoned.

She remained our friend until she died; and we will remember her with love and gratitude always.

I would like to mention two other points connected with professionals and their impact upon us.

I interviewed the psychiatric social worker who had been on the clinic "team." In discussing my husband, he told me: "I liked him."

This is an interesting--and important--comment, I think.

The self-image of parents of handicapped children, of whatever variety, is bound to suffer--at least, at first. None of us is so secure in his or her psyches that abnormal children do not affect his or her self-esteem in some way--no matter how narcissistic or irrational that sounds. Professionals who are able to like their clients offer them something beyond objective scientific therapy. I realize that this may not always be possible--but it's something to think about.

My final point deals with the psychiatrist I saw in Boston.

As I reached the door of his office at the end of my first session, he said, "Mrs. Singer, you don't have to feel guilty."

But I was not ready to accept this. One does not erase guilt as easily as that! After all, from Ypsilanti to Children's Hospital, from Dr. Phelps to Dr. Bettelheim--the verdict seemed to be unanimous: an upset child was the creation of his parents.

Oh, yes--one of my dearly-beloved relatives had sent me a copy of Bettelheim's LOVE IS NOT ENOUGH. It nearly put me over the edge.

According to Bettelheim, it was very bad not to love your child; but on the other hand, too much love was worse. Damned if you did, and damned if you didn't.

My psychiatrist's absolution made me suspicious of him. Could he really be such a good psychiatrist if he didn't recognize how bad I was? Who was he to assure me that I didn't have to feel guilty?

Yet he did accept me! I began to peer out from beneath the clouds of guilt which had settled around me. It was possible to try to see what the problem really was.

Having touched bottom, I was able to swim back to the surface, to face a life which still had possibilities, enjoyment, and hope.

INADEQUATE PROFESSIONAL APPROACHES

The experience presented by Joshua's parents was a common one for many years. Although, with the proliferation of appropriate services for autistic children and the increasing awareness of autism as a developmental disorder (Schopler & Mesibov, 1987), such stories are less frequent, there remains a tendency within the mental health and related fields to not work with parents on a basis of mutual trust and respect.

A starting point for such a working relationship is the recognition by the professional that the parents have important and reliable information to share about their child. From the information presented by Mrs. Singer, it is clear that Joshua demonstrated the major features of autism: significant problems in communication, social relatedness and response to the environment. Professionals responsible for the evaluation of such a child need to first be knowledgeable about the condition of autism, have appropriate methods to evaluate the disorder and be able and willing to understand the parent perspective and communicate results of the assessment (Marcus & Schopler, 1987). In Joshua's case, a proper evaluation was not conducted, nor were the observations or opinions of the parents taken into account. The result was delay in necessary services and enormous additional stress on the family.

The problems faced by this family in trying to get help from the professional community are representative of many such situations in and outside of the United States. The following inappropriate professional responses are illustrated.

Blame and Scapegoating of Parents

A typical first response of the insensitive clinician is to blame the parents for the child's problems. This "scapegoating" is often the result of professional misunderstanding of the diagnosis of autism and the failure to realize that the child's deficits are the reason for his or her deviant behavior and not parental mismanagement (Schopler, 1971; Schopler, Mesibov, Shigley, & Bashford, 1984). A second reason for such blaming is the theoretical or belief system of the professional which may assume that nearly all childhood disorders are caused by inadequate environments and that the necessary treatment is to change the environment. For psychodynamically-oriented therapists this usually means treating the parents psychotherapeutically in an attempt to help the parents overcome their own personal problems that are affecting the child's development. In autism, this belief is harmful to the successful intervention with the child and the family. Parents are made to feel even more guilty than they naturally have at the point at which they sought help. In addition, such beliefs usually do not result in the type of practical advice and service needed with these children.

Failure to Share Information Openly

The doctors involved with Joshua's parents did not reveal their opinions or share honestly and openly their clinical judgments. The results of this secret approach were to build a barrier between the parents and themselves, destroying the important trust, and to lose out on useful information that only the parents could provide. Professionals conducting a comprehensive assessment cannot exclude the parents from access to their conclusions without doing damage to the parent and professional relationship. Professionals sometimes feel that parents will be too

upset by "bad news" (Marcus, 1977) and should be protected from the truth. In fact, parents usually have imagined far worse interpretations of the data and failing to share test and other evaluation results only generates more fear and worry.

Lack of Parent-Professional Partnership

The relationship that typified the manner in which Joshua's parents were dealt with precluded a mutual, respectful partnership. Such nonmutuality puts parents at a significant disadvantage and, ironically, renders the professional far less effective. Parents have a deep and wide range of expertise on their child; the professional often has expertise on childhood disorders such as autism and helpful methods of treatment. However, when the professional acts like the only member of the team and, in effect, accords second class status to the troubled family, the parents are unable to gain or sustain the confidence and energy needed to cope with their situation. The professional also ends up taking more responsibility than necessary by being the "expert" and usually gives up or further blames the parents for the lack of progress.

Permissive Approach to Treatment

Traditionally professionals who have dealt with autistic children have been confused by the nature of the disorder and ways of treating it. Because of the assumption of an emotional disturbance (illustrated by the interpretation of Joshua's problems), the usual suggestion involved removing all pressures and demands. Thus parents, such as the Singers, were told to be permissive and set virtually no limits. Unfortunately, with a developmental disorder such as autism that type of approach is the opposite of what is needed, namely highly structured and governed by rules and routines. Such an approach is required because of the problems in communication, cognition, organization and attention that is common to autistic children. The faulty assumption of autism as an emotional disturbance has

led to poorly conceptualized and designed treatments and to unproductive efforts such as was described earlier.

Transient Nature of Professional Involvement

As was pointed out by Mrs. Singer, parents are the full time and long term responsible individuals in their handicapped child's life. Autism is both a pervasive and chronic disorder and while many professionals may become involved at different stages in the life of the child and family, only the parents have the enduring commitment (Marcus & Schopler, 1987). Despite this, as was noted in Joshua's case, many professionals often seem to take the position that their involvement is more genuine and permanent than the parents. By assuming ownership of the child's problems and solutions, even if the intention is sincere, the professional has excluded the parents from the treatment process and made the future even more difficult for them. When the professional terminates the relationship, as is inevitable, the parents are again alone in their struggle without any more preparation for what to do on a day to day basis than before.

THE TEACCH MODEL

Partly in response to the inadequate and ineffective attitudes and approaches exemplified by the above, the TEACCH program in North Carolina (Treatment and Education of Autistic and related Communication-handicapped Children) was established to foster the development of autistic children through positive collaborative work with families (Runck, 1979; Schopler et al, 1984). Instead of exclusion, parents were brought directly into the treatment process as co-therapists (Schopler & Reichler, 1971). Instead of being treated in a secondary role, parents were considered partners in the program. Instead of permissive approaches, autistic children were provided with structured and individualized

educational methods, based on cognitive behavioral and developmental concepts and strategies (Schopler, Reichler, & Lansing, 1980). Instead of short term and one sided professional involvement, TEACCH staff remains committed to long term support to families to whatever extent is necessary.

The next section will review the main components of the parent training and support program that address the needs of families of autistic children.

Involvement in the Diagnostic Process

From the time a referral is made to TEACCH, parents are involved closely in the diagnostic and assessment process. Parents are asked about their main concerns and for their observations on their child's communication, social and play patterns. Regardless of the questions they raise or the perceptions they have, TEACCH staff respect the parent viewpoint and make every effort to communicate our understanding of the situation. Parents find comfort in knowing that TEACCH has extensive experience with a wide variety of autistic children and that their worries will be acknowledged. During the evaluation process parents' reports are given as much weight as the child assessments in drawing diagnostic conclusions. Their questions form the basis of the interpretative conference which is an open and honest exchange of information (Marcus & Schopler, 1987). The explanations of the diagnoses of autism and mental retardation are given with candor but sensitively. Prognostic implications are addressed as much as possible. Finally specific and practical recommendations are made because the matters of how to help with communication or behavior management are usually the main concerns brought to the evaluation by the parents. A beginning treatment plan is presented on this diagnostic day. By the end of the day, parents are often exhausted and sometimes upset by the news of their child's condition, but grateful for the direct answers to important questions and hopeful that meaningful services will be provided.

Involvement in the Treatment Process

Participation in the treatment process is the logical sequel to the evaluation. Called the extended diagnostic at TEACCH, intervention is primarily based on education and behavior management using principles of child development, behavior modification and a wide range of procedures found useful with autistic children. More importantly, each intervention plan is developed jointly with parent input and collaboration. The primary treatment strategy is through the use of a home teaching program which is demonstrated by a staff therapist for the parents (Schopler et al, 1984). They work on this program, which is written out, at home, typically on a daily basis. The goals are to help with the various areas of deficiency and to strengthen better areas. Parents gain confidence in their teaching, management and child rearing skills. They also learn more about their child to become effective advocates. Staff also provides emotional support and continue to try to answer the many questions that arise during the sessions. The close working relationship between parents and the TEACCH professionals is a genuine partnership that prevents the types of misunderstandings and mistrust that affected the Singer family.

Involvement in Community

The recognition that autism is a pervasive disorder of development means that the professional cannot be satisfied that the clinic is the only setting to provide treatment. TEACCH puts considerable effort in developing, monitoring and consulting to community-based services that benefit the child and the parents. A significant factor in the partnership with families is collaboration in finding or creating services. From the beginning in the mid-1960s, TEACCH and parents worked together to establish clinic services, classroom programs, summer camp experiences, group homes and other community living settings, and, more recently, vocational options. The close working relationship in the clinic expanded, when needed, to the various sectors of the community where the child and family lived. TEACCH

staff has always known that it was not sufficient to simply give some suggestions or make pronouncements without fully backing up the recommendations with a commitment to see the necessary service provided. Parents and TEACCH professionals work on committees together, deal with state agencies and political bodies together and support one another in the endless task of building the total set of structures required for autistic individuals to live productive lives.

Continuity of Service over Time

The chronic nature of autism dictates a plan of action and care that almost always covers the life span of the individual. Since autism does not disappear with adolescence or adulthood, parents need continued support as their child grows older. TEACCH's partnership with parents follows this developmental perspective (Marcus & Schopler, 1987) and our role adjusts to the changing conditions and needs of the family. With the parents of the young child, attention is focused on diagnostic and early intervention issues. The latency years emphasize the school experience and behavioral problems that may surface. Adolescence brings on new concerns, fears and management problems. For many, the question of the permanency of the disorder becomes clearer and possibility of out-of-home placement may be considered. With adulthood, pressure for alternative residential programs intensifies and, with the conclusion of the public school services, vocational settings have to be found. At each of these stages, TEACCH has been available to the families for advice and counseling or, as mentioned above, whatever direct action may be needed. It has often been helpful to put parents in touch with one another. During the preschool years, parents benefit from the sharing of basic information and the awareness that their situation, while painful and potentially isolating, is not unique. During the later years, parents draw strength from one another in confronting the challenges of struggling for improved residential and vocational programs. TEACCH has served in a facilitative role with parent groups.

Virtually every high quality service in North Carolina is the result of the combined efforts of state and local parent groups and TEACCH, from the preschool age through the adult years.

CONCLUSIONS

Professionals who deal with families of handicapped children can be compared to stations on a moving walkway. Families get off at successive stations on this walkway, seeing, amongst others, pediatricians, social workers, psychologists, psychiatrists, teachers, and camp directors.

Professionals vary in their technical competence, and in their intrinsic personalities. Some are intuitive, empathetic, innovative; others are not. Some are au current in regard to philosophies dealing with etiology and treatment; others couldn't care less.

Some parents may have the personal and marital strengths to struggle with their problem. Others may not.

The essential difference between professionals and parents is that the family exists for the purpose of nurturing its children, and this is its permanent, life-long concern. The professional, on the other hand, exists for both the family and the child. Usually this is a relatively temporary concern; in only rare cases will it carry through a lifetime.

What matters is that during the period, whether it be long or short, when we parents and professionals meet, we learn to look at each other as colleagues, working together; that we acknowledge our mutual dependence, our mutual fallibility--and our mutual good-will.

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